

**West Sussex County Council and Partner Organisations**

**Parent Carers Planning Group**

**Notes of the meeting held on 21<sup>st</sup> April 2010  
At 10.30am at Brinsbury College**

**Present:**

Jon Philpot	Principal Manager Special Needs and Disability
Ric Turney	Principal Adviser Special Educational Needs
Gemma North	Admin Assistant, Parent Partnership Service (Minutes)
Dame Philippa Russell	Chair of Government, Standing Commission on Carers
Pat Arculus	Cabinet Member for Children and Young People's Service
Aaron Gain	NHS West Sussex
Judy Howard	Project Manager, Learning
Steve Large	Senior Carers Support Worker
Nigel Scott-Dickerson	Manager, Springboard
Jenni Herrett	Kangaroos
Bill Hargood	VSLDO
Dan Cheesman	Parent Participation Lead, Aiming High for Disabled Children
Bernie Daly	Mencap and Wellspring
Sue Berry	Connexions
Lindsey Butterfield	West Sussex Parents Forum/Parent
Kelly Willard	West Sussex Parents Forum/Parent
Kim Paul	West Sussex Parents Forum/Parent
Ranti Fallowfield	West Sussex Parents Forum/Parent
John Corr	Parent
Janice Knapp	Parent
Michelle Burdis	Parent
Natalie Biegstraaten	Parent

**Apologies:**

Heather McIntosh	Parent Partnership Officer
Liz Hall	CEP, ICIS: information for life
Caroline Johnston	Chair Person, You can do it!
Debbie Buckwell	Service Manager, Aiming High for Disabled Children
Lynda Bell	Acting Service Manager, Child Disability Team
Carys Wreyford	Early Childhood Service
Liz Squire	Parent

## **1. Welcome, Introductions & Apologies**

Jon Philpot welcomed everyone and explained that he would be chairing the meeting. He also introduced Dame Philippa Russell to the group. The group then introduced themselves.

## **2. Matters arising from Minutes of 20<sup>th</sup> January 2010**

Jon explained that he would be talking about Aiming High for Disabled Children in the Any Other Business and that the West Sussex Parents Forum was on the agenda.

There weren't any other matters that arose from the previous minutes.

## **3. Feedback from Parents Forum (Lindsey Butterfield)**

Lindsey firstly stated that there was a new newsletter and handed them around the room.

She reported that the Parents Forum had been very busy since the meeting in January. She explained that they had been involved with the Parental Confidence project with Judy Howard and that they'd had a meeting and a draft charter had been drawn up. Judy explained that there was a probability of a conference in autumn as an outcome.

Lindsey reported that the Parents Forum attended the AHDC Universal Services event at Chichester College on 31<sup>st</sup> March that was attended by 100 people. They gave a short presentation and said the feedback they'd received was very positive and that it was a very successful event in which parents and carers and professionals came away wanting to make positive changes.

Lindsey briefly mentioned that they are still involved with Early Years Support and that they were attending ongoing meetings.

Lindsey reported that they'd received positive feedback about the draft proposed Transport Charter and that they'd sent it on and are currently waiting to meet with Ian Gwenlan regarding this.

Two members of the West Sussex Parents Forum committee attended the Children's and Young People's Services Select Committee meeting in Chichester, in which they presented to members how Aiming High was changing the lives of families with disabled children and how it needs to be moved forward to carry on providing activities and short breaks for these children for the future.

Ranti explained that she had attended the Aiming High conference and that the highlight was Ed Balls speech. She said that she attended the National Parent Support Workshop and that she thought it had been a fantastic day. One of the things she learnt that was of interest was that WS aren't behind, as she'd feared and that they're actually on par with other counties.

Lindsey brought the groups attention to a free Parent/Carer Information Event held by the Parents Forum. It is on Tuesday 11<sup>th</sup> May between 7pm & 9pm at Palatine School. Many organisations and providers who help support children with special needs and disabilities will attend the event and parents/carers will have the opportunity to talk to these organisations and get information, as well as chat with other parents about their experiences.

Lindsey mentioned a question and answer session at Billingshurst Village Hall on Thursday 17<sup>th</sup> June. Parents have the opportunity to put their questions to the Parents Forum before the day, which will be passed onto the panel in advance and will be answered on the day.

#### **4. Disability Review (Dame Philippa Russell)**

Philippa Russell introduced herself and explained a bit about what she did. She said that the Disability Review was initiated by NHS West Sussex. She explained the Disability Review with the aid of a PowerPoint presentation (attached).

Philippa explained the background and objectives of the review which include a critique of existing services to children with complex long-term needs, the identification of future needs and services, the understanding of patients needs as well as carers needs with recommendations for improvement and change. Philippa explained that West Sussex is regarded as a "complex jigsaw" as it is a large county. The need to look at future demands is because there is a relocation of people to West Sussex and the need to actively involve parents and carers to support their needs as well as the child's.

Philippa said that the review will focus on children with complex long-term health needs, so if they can improve services for them, then the less complex needs should be able to be helped too. Reviewing the system of care provided rather than a detailed analysis of a couple of cases, so that all services will be looked at and regarded rather than focussing on individual case studies. The review will also include some case study work, though. Philippa explained that reviewing the understanding of how services are delivered by all providers would aid in the arrangements for commissioning of these services too.

Philippa said that consultations had already taken place in the form of 2 parent/professional consultations and a parent survey. She reported that 112 parents have responded to the survey and that more are still coming in. As well as consultations of parents and carers, they are doing ongoing interviews and visits with key commissioners and providers. Philippa said that the key messages that had come from the consultations were that parents wanted a single person that would make sense of the journey for them and that parents wanted a 'team around the child' in which, at least annually, all professionals that worked with the child would meet to review their needs. Parents said they would preferably like this to take place in the child's school as this is where the child does their work. Philippa showed a quote from one of the parents, which reminds us that families are constantly working hard for their children and that they're tired because of it.

Philippa then went on to explain how the review hopes to tackle the problems so that WS get it right from the start when dealing with a child with disabilities. She said that in order to do this they will firstly focus on developing the Early Support Programme and Early Referrals.

Philippa explained that the consultations had shown that Aiming High for Disabled Children, in particular, was working well within WS because parents felt that they realised that it's about helping the family as a whole and not just the child with disabilities. She explained that certain individuals had gained praise for "going the extra mile" and that the short

breaks/respite care (including the sitting and buddying services) were good in quality, but that parents felt that there weren't enough services like them for all of WS needs.

Philippa then went on to explain that the review plans to look at families in context, with focus on personalisation, partnership and co-production. She said that they wanted to develop a 'road map' from initial diagnosis and discharge, as well as improving the communication between services and support for the families. Philippa explained that the consultations said that parents wanted help, not all the time but when it is really difficult. Philippa explained the challenges and problem areas in improving services focussed around equipment, incontinence service and transport. With equipment parents felt that they weren't dealt with quick enough and that the attitude of some staff was unhelpful. Parents had a general dissatisfaction with quality and quantity of incontinence supplies and would prefer individual budgets or direct payments to be able to get the supplies. They felt that they just wanted WS to facilitate the ability for families to go out with their children. The transport issues were that there was not enough of it in such a big county with vast amounts of rural areas and that parents felt they had to arrange further services just for their children to partake in after school activities. Philippa explained that other challenging areas were transitions, at all stages, where there was not enough consistency and continuity of care from one stage to the next and that children were 'surviving' through school. Also, that there were shortfalls with speech and language, physiotherapy and occupational therapy services. Philippa explained that parents recognised there were problems with recruitment in these areas but wanted to develop a 'consultant outreach role', particularly in school situations. Parents understood that there are budget concerns, but wanted honest discussions about this with the statutory agencies.

Philippa said that the barriers to improvement that the review saw were the 'mismatch' of catchment areas between the LA, education and health services. Other barriers include the repercussions of previous 'reorganisations', which parents felt was something the LA did to make people think they are making changes without addressing the real issues. Another barrier was the difficulty of employing more therapists in various services and improving links between community services and specialist providers.

Philippa explained that the way the review plans to go forward is to provide equal treatment, not in the case of treating everyone the same, but in recognising that everyone's needs are different, and tailoring the correct provisions to their specific needs. Other ways forward were to have openness and transparency with allocation of resources, realistic short, medium and long term goals and to give families maximum choice and control so that they can all enjoy a good quality of life together.

Finally, Philippa explained what the review hopes to achieve, which is understanding current practices and improving parents experiences of these, as well as creating a better understanding for both parents, and professionals across the board involving a wider range of stakeholders. Aaron Gain from NHS West Sussex then briefly explained the two next steps of the review. Firstly, to look at the financial projections, which involves finding out all resources that are spent on a child. Secondly, to look at the future patterns of need. Looking at how much WS has now,

and how quickly that is likely to increase within so many years and what kinds of needs that will need to be addressed in forthcoming years.

After Philippa and Aaron had talked, Jon then opened the floor up to questions. Some key points that arose were:

Kim Paul asked 'what group of children do you mean by complex needs/disability?' Philippa explained that the focus would be on children with a multiplicity of interlinked conditions, and that by improving provision for them they can improve from 'high-level'.

Natalie Biegstraaten said that the changes within WS were not always filtered down to parents and that they should be better informed, as they are the ones holding everything together.

Michelle Burdis said she felt that education and health couldn't work together and that they were constantly 'bickering' about who was going to pay for what, so it never got paid, and the parent doesn't have any power to do anything about it.

Nigel Scott-Dickerson said regarding co-production, that there was a responsibility of providers to have better consultations with the children themselves and mentioned the 'My Health, My Choice' publication.

Pat Arculus mentioned the youth cabinet, which Kim Paul said she felt some young people, didn't want to do because they didn't want to be the 'token' disabled person.

## **5. Any other business**

### Aiming High for Disabled Children

Jon Philpot gave a brief update on AHDC. Jon gave around a handout regarding the national indicator NI54.

Jon also distributed a new short breaks provider's list.

Jon also mentioned another Family Fun day to be held on 4<sup>th</sup> July at Lancing Manor Leisure Centre.

He also mentioned that they were currently advertising for a Parent Co-ordinator with regards to the PAT mark.

Jon explained that AHDC were looking into the I-Count Card and that Debbie had met a colleague from PCT and that they would have to sign up on a 3-year basis. This would not be possible until the funding position after Mar '2011 was clearer. He said this was ongoing.

### LAMB Inquiry

Ric Turney explained that WS had not been selected for the grant and that he was currently looking into finding out why.

Bernie Daly mentioned Merlin's Magic Wand, which aim to give children who are seriously ill, disabled or disadvantaged the opportunity to enjoy attractions that they may otherwise not have been able to do, such as Alton Towers, London Eye, Legoland, Madame Tussauds and Sealife. You can email [hilary.birkinshaw@merlinentertainments.biz](mailto:hilary.birkinshaw@merlinentertainments.biz) for an application for attraction tickets, or visit [www.merlinsmagicwand.org](http://www.merlinsmagicwand.org).

Bernie also mentioned that the Family Fund can now give grants for severely disabled children up to the age of 18 in England, Northern Ireland, Wales and Scotland. For more information and to apply, go to:

[www.familyfund.org.uk](http://www.familyfund.org.uk) or email [info@familyfund.org.uk](mailto:info@familyfund.org.uk) or call 0845 130 4542.

Bernie also gave details of Family Fund Extra. All families with a disabled child, as well as disabled young people themselves up to the age of 25, can join Family Fund Extra for free and enjoy discounts of up to 25% from online retailers including Argos, Comet, BSM, Haven Holidays and Stone Computers. Also, anyone who shops online can help severely disabled children at no extra cost by clicking through the extra website to nearly 100 retailers. For more information, visit [www.familyfundextra.org.uk](http://www.familyfundextra.org.uk).

## **6. Date and time of next meeting**

Wednesday 14<sup>th</sup> July 2010, 10.30am – 12.30pm, with a buffet lunch provided from 12.30pm – 1pm. Meeting to be held in the Conservatory Room, Brinsbury College.

## **7. Items for next meeting**

CAF  
CAMHS  
Play Strategy update